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Trajectories of disposable income among people of working ages diagnosed with multiple sclerosis: a nationwide register-based cohort study in Sweden 7 years before to 4 years after diagnosis with a population-based reference group

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ABSTRACT

Objectives To describe how disposable income (DI) and three main components changed, and analyse whether DI development differed from working-aged people with multiple sclerosis (MS) to a reference group from 7 years before to 4 years after diagnosis in Sweden.

Design Population-based cohort study, 12-year follow-up (7 years before to 4 years after diagnosis).

Setting Swedish working-age population with microdata linked from two nationwide registers.

Participants Residents diagnosed with MS in 2009 aged 25–59 years (n=785), and references without MS (n=7847) randomly selected with stratified matching (sex, age, education and country of birth).

Primary and secondary outcome measures DI was defined as the annual after tax sum of incomes (earnings and benefits) to measure individual economic welfare. Three main components of DI were analysed as annual sums: earnings, sickness absence benefits and disability pension benefits.

Results We found no differences in mean annual DI between people with and without MS by independent t-tests (p values between 0.15 and 0.96). Differences were found for all studied components of DI from diagnosis year by independent t-tests, for example, in the final study year (2013): earnings (−64 867 Swedish Krona (SEK); 95% CI −79 203 to −50 528); sickness absence benefits (13 330 SEK; 95% CI 10 042 to 16 500); and disability pension benefits (21 360 SEK; 95% CI 17 380 to 25 350). A generalised estimating equation evaluated DI trajectory development between people with and without MS to find both trajectories developed in parallel, both before (−4039 SEK; 95% CI −10 536 to 2458) and after (−781 SEK; 95% CI −6988 to 5360) diagnosis.

Conclusions The key finding of parallel DI trajectory development between working-aged MS and references suggests minimal economic impact within the first 4 years of diagnosis. The Swedish welfare system was responsive to the observed reductions in earnings around MS diagnosis through balancing DI with morbidity-related benefits. Future decreases in economic welfare may be experienced as the disease progresses, although thorough investigation with future studies of modern cohorts are required.

Strengths and limitations of this study

- The main strengths of this study include both the population-based design and use of nationwide registers with high completeness and validity, which enabled measurement of multiple sources of income of a recently diagnosed multiple sclerosis (MS) cohort.
- The longitudinal study design with repeated measures enabled the study of the development of disposable income for working-aged people with MS prediagnosis and postdiagnosis, in addition to the difference in annual levels of different income sources to a population-based reference group.
- While residual confounding cannot be excluded, the reference group was a randomised stratified matched group from the general population at a ratio of 1:10.
- An important limitation is that this study does not address the long-term association between economic welfare and MS, as the follow-up was only 4 years in the postdiagnosis period.

INTRODUCTION

Multiple sclerosis (MS) is the leading cause of non-traumatic neurological disability in younger adults.[1–4] People with MS (PwMS) in Sweden have a mean onset age of 33 years for first symptoms, but experience a time-lag of 6–7 years before receiving a formal diagnosis with this chronic and progressive disease.[5]

Previous research has found MS to be associated with progressive work incapacity, due to physical disability worsening as time from onset increases.[5–11] Therefore, levels of absenteeism, with high proportions working part time and exiting paid work, and presenteeism, with reduced work productivity, increase over the disease course.[5 9] However, there is uncertainty and variability among PwMS in progression to disability milestones.[12] The indirect costs of working-aged PwMS become a dominating cost as the disease progresses from a societal perspective.[5 13–15] Nonetheless, the impact of MS on the individual's economic welfare remains relatively unknown.

Earnings remain an important income source for PwMS.[3 16] However, earnings alone provide an incomplete picture of an individual's economic welfare, limited to describing the individual's labour market participation and income generation.[3 16] A recent Swedish survey found that 77% of PwMS worked part time, and participation in paid work rapidly decreased with advancing disease.[5]

The wider socioeconomic context can mediate the economic impact of MS on the individual.[17 18] The Swedish welfare state aims to protect individuals with chronic disease from economic pressure through universal healthcare and social insurance benefits. The most substantial of these benefits for PwMS are the temporary sickness absence (SA) and permanent or long-term disability pension (DP) benefits; both designed to compensate a proportion of previous earnings reduced by morbidity-related absence.

There is a growing body of evidence of the positive associations between MS progression in terms of physical disability and cognitive function with the morbidity-related benefits.[19–22] Furthermore, a substantially higher proportion of PwMS receive SA and DP, in comparison with the general population.[3 21 23] These changes in sources of income are observed to often occur within a few years of symptom onset, indicating that morbidity-related benefits are necessary to consider when investigating the economic situation of working-aged PwMS.[16 24–26] However, the collective impact of these changes in incomes to the individual's economic welfare is largely unknown. Thorough investigation on how MS affects the economic resources available to PwMS in Sweden necessitates the need to longitudinally assess multiple sources of income in totality.[3 21 23 27–30]

Disposable income (DI) is composed of multiple income sources, enabling a comprehensive nuanced description of economic welfare that better reflects an individual's consumption potential than the individual income sources.[3 31] DI is the 'sum of factor income (income from work and capital) and net income from transfers (government benefits), minus income taxes, and fees paid to the government'.[16] Despite an increasing number of studies on PwMS receiving SA and DP benefits or about earnings, little is known about how MS impacts one's DI trajectory development in a welfare state.[3 20 21] Longitudinal Danish studies have applied DI concepts by combining both earnings before tax and DP benefits, but not income from SA benefits, to suggest PwMS maintain similar trajectories while remaining in paid work.[25 32] Nevertheless, the full magnitude of the current economic consequences for individuals with MS remains unknown in the Swedish welfare state where the context for MS has changed substantially in recent years due to treatments delaying disability progression and policy environments for SA and DP grants.[33–35]

This study aimed to describe the development of DI and three main components (SA, DP and earnings) among working-aged people diagnosed with MS in the years immediately before and after diagnosis and compare with people without MS, in order to gain knowledge on the economic welfare of working-aged people diagnosed with MS in a welfare state.

METHODS

Study design

We conducted a cohort study to measure the levels and development of mean annual DI and its main components (SA, DP and earnings) among PwMS aged 25–59 years at diagnosis in Sweden, in relation to matched references without MS. The index year of diagnosis, 2009, is presented as Y_0, with the 7 years of observation before and 4 years after diagnosis as Y_{-7} to Y_{-1} and Y_{+1} to Y_{+4}, respectively.

Data sources

Person-level data were obtained from the following two nationwide Swedish registers:

1. *Longitudinal Integration Database for Health Insurance and Labour Market Studies* (LISA), held by Statistics Sweden, was used to obtain sociodemographic variables and the sums of annual income from the different sources across follow-up.
2. *National Patient Registers*, held by the National Board of Health and Welfare, enabled identification of all people with an MS diagnosis. The registers contain healthcare visits for inpatient treatment by the International Classification of Diseases (ICD) codes, ICD 9th Revision (340) and ICD 10th Revision (ICD-10) (G35) (1987–2009), and specialised outpatient treatment by ICD-10 (2001–2009).

The linkage of data was performed using the unique personal identity numbers assigned to every resident in Sweden.

Study population

The study population was sourced from the total population registered as living in Sweden on 31 December 2009 (from LISA). The cohort of PwMS included all 785 PwMS identified with an incident MS diagnosis in 2009 and on 31 December 2009 aged 25–59 years. The age range allowed for the cohort to be of working ages in all studied years, with 65 years being the customary age for old-age pension in Sweden. All people with their first MS diagnosis according to the National Patient Registers in 2009 were included, excluding all with a previous MS diagnosis

(according to the inpatient and specialised outpatient registers).[23]

We established a matched reference cohort of people who before 2010, according to the inpatient and specialised outpatient registers, were not diagnosed with MS. Among all without MS who, according to LISA, lived in Sweden 31 December 2009, we randomly selected 10 references for each PwMS, matched on age, gender, educational level and birth country in 2009 (Y_0). This produced a stratified matched reference group with the same distribution of the selected sociodemographic variables in Y_0 to the MS cohort. The 1:10 ratio of references could not be met for one individual with MS, with only seven possible references in the general Swedish population matching the particular combination of sociodemographic variables. In all, 7847 references were included at Y_0.

The maximum number of years of observation was 12, with 97.3% (n=764) of the PwMS and 97.8% (n=7671) of the reference group in the study at the end of follow-up (Y_{+4}). Missing income data in LISA, due to migration before/after the index year or death after Y_0, led to small proportions of individuals across both groups not being followed for the entirety of follow-up.

Patient and public involvement

This was a study based on national register data, and there was no patient or public involvement.

Variables

Our main outcome measure was annual DI. We used the DI measure constructed by Statistics Sweden, contained in LISA. This was the sum of incomes after tax, with sources including: income from work and public benefits such as DP, SA, disability allowance, unemployment compensation, old-age pension and social assistance.[36] DI was an individualised measure of household DI, calculated as the sum of household incomes, adjusted for household size and the individual's consumption weight to produce a continuous variable.[36]

The three main components of DI for working-aged PwMS were also included as secondary economic outcomes in analyses as the mean annual sum:

- SA: all people living in Sweden above the age of 16 years are covered by public sick-leave insurance if they receive income from work or unemployment benefits and, if due to disease or injury, have work incapacity. The Social Insurance Agency pays the granted SA benefits, of up to 80% of lost earnings, at 100%, 75%, 50% or 25% of ordinary working hours. Among employees, the employer provides sick pay in the first 13 days of a sick-leave spell after the first uncompensated day.
- DP: all residents aged 19–64 years can be granted DP if disease or injury leads to long-term or permanent work incapacity. Benefits of up to 64% of the lost earnings are paid by the Social Insurance Agency, at 100%, 75%, 50% or 25% of ordinary working hours.
- Earnings: income from work was in the form of gross earnings (before tax deductions). This included the sick pay provided by the employer during the first 14 days of a sick-leave spell.

Earnings were presented in gross form, and only two potential public benefit payments were included in the analyses; therefore, one cannot sum the three components to the presented DI values. All monetary values were presented in Swedish Krona (SEK) and adjusted for inflation by the Statistics Sweden Harmonised Consumer Price Index (HCPI) by the annual average 2016 value.[37]

The following sociodemographic variables, sourced from LISA, were included in the analyses as explanatory variables:

- Age (continuous, time variant): in addition, age was also computed into a new continuous variable to control for curvilinearity in the statistical analyses by squaring the values for age.
- Gender (binary).
- Educational level (categorical, time variant: elementary; high school; college or university; and missing).
- Birth country (categorical: Sweden, other Nordic countries, other EU25 countries; rest of world and missing).

The study cohort had near complete data with less than 0.25% missing values for country of birth and 0.5% for educational level.

Statistical analyses

Data management and statistical analyses were conducted in SAS V.9.4, with the exception of generalised estimating equation (GEE) models, which were calculated in SPSS V.24.

In our data management, we set 337 negative DI values between 2004 and 2013 to zero to prevent distortion of the DI means over time. This was required as Statistics Sweden changed how they coded DI in LISA; earlier years of follow-up had a lower limit of zero, but negative values were possible from 2004. We trimmed extreme outlier DI values at 566 100 SEK, representing the 99th percentile of annual DI across all study years. This made the distribution of DI reasonably normal for statistical analyses. Individuals with missing values in LISA for DI and the secondary outcomes, in years other than Y_0, were excluded in descriptive statistics for the respective years but were included in the GEE model. Earnings were also capped at the 99th percentile (810 400 SEK) to control for extreme outliers.

Descriptive statistics were performed to describe the distribution of sociodemographic variables and summarise the levels of the different incomes. Categorical data were expressed as frequency distributions with the number and percentage. Continuous data were reported for both the PwMS and the reference group, expressed by the mean, 95% CI and both the number and proportion with annual sums >0.[38]

The means of annual DI of PwMS was calculated for each year, Y_{-7} to Y_{+4}. The differences in mean annual DI

of PwMS were tested for statistical significance by dependent t-tests between the following three time points: Y_{-7} to Y_0; Y_0 to Y_{+4}; and Y_{-7} to Y_{+4}. Independent two-tailed t-tests with Satterthwaite approximation for unequal variance were performed for each year of follow-up to test the difference in mean annual DI between PwMS and the references. The mean differences in annual sums of earnings, SA benefits and DP benefits between PwMS and references were calculated with 95% CI at three time points: Y_{-7}; Y_0; and Y_{+4}.

Lastly, we conducted linear regression analyses, using the GEE method to analyse how MS influenced the DI trajectory development over the study period.[39] The GEE models described the difference in the slopes of the DI trajectories from Y_{-7} to Y_{+4} between PwMS and the reference group. The method allowed for the dependent repeated measures of DI by accounting for the clustering of observations at both the individual and group levels that violated independence assumptions.[39–41] The dependent variable, DI, was analysed as a continuous measure. The DI distribution was slightly right skewed, but GEE is a robust method.[40] The GEE models were computed with the following specifications: a normal distribution, identity link and autoregressive within-subject correlation. The within-subject correlation structure was selected because of the reasonable assumption that the correlation between an individual's annual DI values diminished over time. The models were adjusted for gender, age, education level and country of birth. An additional age variable was included to account for curvilinearity. All variables were entered simultaneously with an interaction term of MS and year to evaluate whether PwMS had a different DI trajectory than the references. The periods prediagnosis and postdiagnosis were assessed in separate models. The GEE model results were presented as unstandardised beta regression coefficients with 95% CI, which can be interpreted as values in SEK. The significance level for all analyses was α=0.05.

RESULTS

We observed growth of annual DI experienced by both the PwMS and the reference group over the study period. There were significant differences between PwMS and the reference group in mean annual sums of SA benefits, DP benefits and earnings along the disease trajectory. No differences in either the levels or development of mean annual DI between Y_{-7} and Y_{+4} were observed.

Table 1 contains a basic description of the study population and shows that the reference group (n=7847) was representative of the PwMS cohort (n=785) on the distribution of these sociodemographic variables. The MS cohort had a mean age of 41 (95% CI 40.7 to 42.0) in Y_0, and a female-to-male ratio of 2.17.

In Y_0, PwMS had a mean annual DI of 177 040 SEK (95% CI 170 170 to 183 920) (figure 1). PwMS experienced a mean increase in annual DI over the 12-year study period of 52 240 SEK (95% CI 44 740 to 59 740).

Table 1 Sociodemographic characteristics of the study population at year of diagnosis (2009)

	MS* n (%)	References* n (%)
	785 (100)	7847 (100)
Sex		
Women	537 (68.4)	5367 (68.4)†
Men	248 (31.6)	2480 (31.6)†
Age group (years)		
25–34	213 (27.1)	2130 (27.1) †
35–44	279 (35.5)	2790 (35.6) †
45–54	208 (26.5)	2077 (26.5) †
55–59	85 (10.8)	850 (10.8) †
Education (in years)		
≤9 (elementary)‡	111 (14.1)	1107 (14.1)†
10–12 (high school)	355 (45.2)	3550 (45.2)†
>12 (college or university)	319 (40.6)	3190 (40.7)†
Country of birth		
Sweden	677 (86.2)	6770 (86.3)†
Nordic countries (except Sweden)	23 (2.9)	230 (2.9)†
EU25 (except Nordics)	27 (3.4)	270 (3.4)†
Rest of the world‡	58 (7.4)	577 (7.4)†

*MS diagnosis first registered in 2009 in nationwide inpatient and specialised outpatient registers. References: matched on variable distribution (1→10) with no registered MS diagnosis in years before 2010.
†Reference group matched to MS cohort on these variables.
‡Individuals with missing variables added to lowest category (<0.5% of both study cohorts).
MS, multiple sclerosis.

This increase in mean annual DI was observed in both the periods before (31 930 SEK; 95% CI 25 770 to 38 080) and after diagnosis (21 730 SEK; 95% CI 15 820 to 27 630) by dependent t-tests.

To further investigate the mean annual DI of PwMS, comparison was made to the reference group. Figure 2 suggests there were differences in mean annual DI between PwMS and the reference group, where the reference group consistently had higher annual DI means, from 4 years prior to MS diagnosis. This suggested gap widened over time. However, independent t-tests suggested that these differences were statistically non-significant (p values ranged between 0.15 and 0.96) (not presented).

Table 2 displays the differences in the mean annual sums of the main components of DI (earnings, SA benefits and DP benefits) between PwMS and references in Y_{-7}, Y_0 and Y_{+4}. In every year, both SA and DP had a median of zero, indicating that most individuals in both groups did

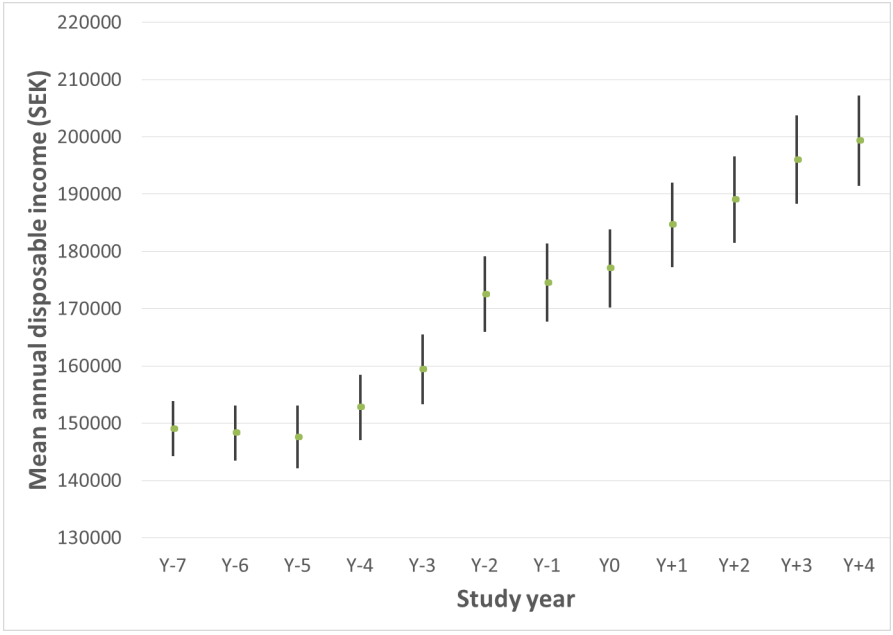

Figure 1 Mean disposable income (DI) Y_{-7} to Y_{+4} among people diagnosed with multiple sclerosis (MS) in Y_0. *Notes:* mean annual DI with 95% CIs illustrated. DI sums are inflated to 2016 values in Swedish Krona (SEK) with the Harmonised Consumer Price Index. In 2017, 100 SEK≈ €10.5. MS, individuals with first registered MS diagnosis in 2009 (Y_0) in national inpatient and specialised outpatient registers.

not receive either benefit (not presented). A trend for PwMS to have greater sums of income from morbidity-related benefits than the references was present from Y_{-7} (DP mean difference: 5571 SEK; 95% CI 1773 to 9369). The proportion of PwMS who received each of the benefits, SA and DP, increased over time. However, substantial skewedness of income from these morbidity-related sources remained even among PwMS; in each year less than 30% of PwMS had annual income from each benefit (except SA in Y_0, 44%). This skewness was larger among the references (<17%). Notwithstanding, in every year studied, the mean SA and DP amounts were higher for PwMS than for the reference group with differences in all years, apart from SA benefits in 2002 (Y_{-7}). PwMS had

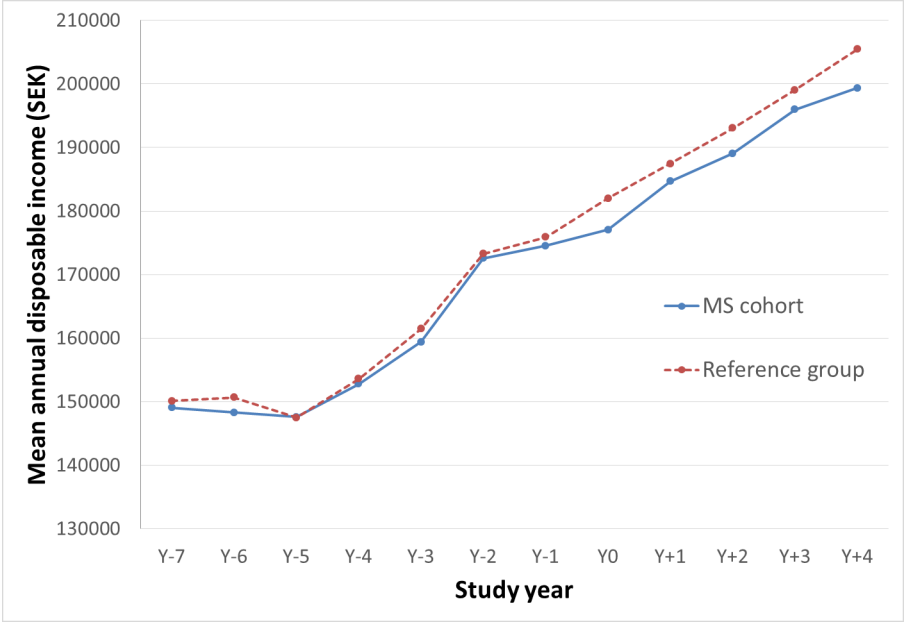

Figure 2 Mean disposable income (DI) Y_{-7} to Y_{+4} among people diagnosed with multiple sclerosis (MS) in Y_0 (n=785) compared with references (n=7847). *Notes:* mean annual DI inflated to 2016 values in Swedish Krona (SEK) with Harmonised Consumer Price Index In 2017, 100 SEK≈ €10.5. Year of diagnosis (2009=Y_0). MS (solid blue line): individuals with first registered MS diagnosis in 2009 (Y_0) in national inpatient and specialised outpatient registers. References (dashed red line: matched on four variables (1→10) with no MS diagnosis registered in years before 2010 in the National Patient Registers. MS, multiple sclerosis.

Table 2 Annual mean sums of income for the cohort of people with MS (n=785) and the cohort of references (n=7847) at Y_{-7}, Y_0 and Y_{+4}*

	MS†			References†			Mean difference	95% CI
	Mean sum‡	95% CI	n (%)§	Mean sum‡	95% CI	n (%)§		
Y_{-7}*			**747**			**7457**		
Sickness absence	10829	(8369 to 12 293)	147 (20)	8523	(7804 to 9243)	1289 (17)	2306	(–257 to 4868)
Disability pension	13966	(10281 to 17 654)	63 (8)	8396	(7480 to 9312)	383 (5)	5571	(1773 to 9369)
Earnings¶	184174	(172691 to 195658)	645 (86)	193918	(190357 to 197467)	6653 (89)	–9742	(–21763 to 2275)
DI¶**	149060	(144180 to 153940)	–	150110	(148530 to 151700)	–	–1051	(–6184 to 4073)
Y_0*			**785**			**7847**		
Sickness absence	26685	(23178 to 30 179)	347 (44)	3995	(3549 to 4442)	811 (10)	22693	(19155 to 26 220)
Disability pension	13548	(10866 to 16 230)	103 (13)	8571	(7871 to 9270)	629 (8)	4977	(2208 to 7745)
Earnings¶	207834	(195427 to 220242)	651 (83)	248352	(244339 to 252365)	6791 (87)	–40 517	(–53 558 to –27 476)
DI¶**	177040	(170170 to 183920)	–	182010	(179750 to 184280)	–	–4971	(–12210 to 2266)
Y_{+4}*			**764**			**7671**		
Sickness absence	19597	(16363 to 22 831)	220 (29)	6263	(5664 to 6862)	963 (13)	13330	(10042 to 16 500)
Disability pension	29269	(25340 to 33 199)	210 (28)	7908	(7226 to 8590)	558 (7)	21360	(17380 to 25 350)
Earnings¶	214426	(200723 to 228119)	582 (76)	279298	(275050 to 283534)	6719 (88)	–64 867	(–79 203 to –50 528)
DI¶**	199350	(191540 to 207160)	–	205450	(202950 to 207950)	–	–6098	(–14300 to 2103)

*Y_{-7}=2002, Y_0=2009 and Y_{+4}=2013.
†MS diagnosis first registered in 2009 in national inpatient and specialised outpatient registers. References: matched on variable distribution (1→10) with no registered MS diagnosis in years before 2010.
‡Inflated to 2016 Swedish Krona (SEK) values by the Harmonised Consumer Price Index. In 2017, 100 SEK≈ €10.5.
§Number count or proportion receiving annual sums >0.
¶Trimmed at the 99th percentile.
**DI is the sum of incomes from earnings and benefits (in addition to SA and DP presented) after tax (net). Earnings are presented as gross (amount paid before taxable deductions) and therefore are higher than the DI presented.
DI, disposable income; DP, disability pension; MS, multiple sclerosis; SA, sickness absence.

Table 3 Disposable income (DI) trajectory postdiagnosis from Y_0 (2009) to Y_{+4} (2013) in the cohort of people with MS (n=785) compared with the cohort of references (n=7847)*†

Year	Adjusted regression coefficient‡§	95% CI
Y_{+4} (2013)	−781	−6922 to 5360
Y_{+3} (2012)	1623	−3839 to 7085
Y_{+2} (2011)	1200	−4120 to 6520
Y_{+1} (2010)	1710	−3226 to 6646

*Reference groups for analysis: 2009 (Y_0) and reference group.
†MS diagnosis first registered in 2009 (Y_0), in national inpatient and specialised outpatient registers, n=785 in 2009. References: matched on variable distribution (1→10) with no registered MS diagnosis in years before and including 2009, n=7847 in 2009.
‡Adjusted for age, gender, education level and country of birth.
§Unstandardised beta. Inflated to 2016 Swedish Krona (SEK) values by the Harmonised Consumer Price Index. In 2017, 100 SEK≈ €10.5.
MS, multiple sclerosis.

Table 4 Disposable income (DI) trajectory prediagnosis from Y_{-7} (2002) to Y_0 (2009) in the cohort of people with MS (n=785) compared with the cohort of references (n=7847)*†

Year	Adjusted regression coefficient‡§	95% CI
Y_0 (2009)	−4039	−10 536 to 2458
Y_{-1} (2008)	304	−6135 to 6742
Y_{-2} (2007)	−715	−6883 to 5454
Y_{-3} (2006)	−2060	−7588 to 3468
Y_{-4} (2005)	−863	−6085 to 4358
Y_{-5} (2004)	258	−4681 to 5197
Y_{-6} (2003)	−1515	−4844 to 1813

*Reference groups for analysis: 2002 (Y_{-7}) and reference group.
†MS diagnosis first registered in 2009 (Y_0), in national inpatient and specialised outpatient registers n=785 in 2009. References: matched on variable distribution (1→10) with no registered MS diagnosis in years before 2010, n=7847 in 2009.
‡Adjusted for age, gender, education level and country of birth.
§Unstandardised beta. Inflated to 2016 Swedish Krona (SEK) values by the Harmonised Consumer Price Index. In 2017, 100 SEK≈ €10.5.
MS, multiple sclerosis.

a peak in SA in Y_0 with the DP benefits increasing in the postdiagnosis period, whereas the references had stable DP sums and proportions across follow-up. From the time of diagnosis Y_0, PwMS had significantly lower earnings than the reference group, with this trend continuing throughout the postdiagnosis period.

Potential differences in the development of the mean annual DI trajectory of PwMS from that of the matched references were assessed with a GEE model. In figure 2, there were indications of the slopes both diverging prior to diagnosis and realigning to develop more in parallel in the years after diagnosis. All results from the GEE model provided non-significant differences between the development of the DI trajectories of PwMS and the reference group. Table 3 contains the differences in DI development after diagnosis in relation to the year of diagnosis and shows that between Y_0 and Y_{+4} was on an average 781 SEK (95% CI −6922 to 5360) less for PwMS than for the reference group. Analysis of the prediagnosis period is contained in table 4, where from Y_{-7} to Y_0 the development of mean annual DI for PwMS was on an average 4039 SEK (95% CI −10 536 to 2458) lower than the reference group.

DISCUSSION

Principal findings

We have presented the mean DI development for working-aged PwMS from 7 years before to 4 years after diagnosis, in comparison with a population-based stratified matched reference group without MS. Our principal finding was that within the first 4 years after diagnosis, there was little change to PwMS' DI trajectory in comparison with those without MS. Both groups experienced parallel trajectory development despite substantial differences in the individual component sources of income: earnings, SA benefits and DP benefits. Changes in morbidity-related benefits balanced the expected gap from reduced earnings to maintain the economic welfare of PwMS over follow-up. The result that both DI levels and development are similar can be interpreted as responsiveness of the Swedish welfare system to the potential economic consequences of work incapacity through benefit payments in the first years after MS diagnosis.

Interpretation of findings

Our interpretations are contextualised within the short term, with observation pertaining to the years early in the disease course. This is of importance in the context of a heterogeneous and progressive disease, where baseline disability and age at onset are predictive of progression to milestones of irreversible physical disability.[35 42]

To situate our findings of DI, a Danish study found differences in the levels of mean annual gross income (pretax sums of earnings and benefit payments but excluding SA benefits) only after 20 years postdiagnosis, where PwMS received 70% of the mean annual gross income of matched references.[25] The difference was attributed to DP benefits (compensated as a proportion of previous earnings) becoming the largest source of income for PwMS by the end of this longer follow-up that allowed for increasing severity of disability and consequent morbidity-related absence from work.[25] Notable differences exist between the Danish and Swedish social security systems and labour markets.[43] However, it is likely that PwMS in Sweden would also experience reduced DI after a substantially longer follow-up allowing for further disease progression, as long-term DP benefits compensate lost earnings

to a lower proportion than short-term SA benefits.[10 25] Earnings remained the main income source for our MS cohort, where 76% cohort still participated in paid work to some degree at the end of follow-up, reflecting findings of Wiberg *et al*[3] that notwithstanding changes in sources of income around diagnosis, earnings remain the dominant source. Furthermore, Pfleger *et al*[25] concluded that PwMS maintained similar levels of gross income to the references while remaining in paid work. The combination of which supports our findings of similar DI trajectories between PwMS and the references in the short term.

Despite the importance of earnings for maintaining economic welfare of working-aged PwMS, reductions in comparison with references were observed to begin early in the disease course. Similarly to Wiberg *et al*, we found that PwMS had lower mean annual earnings than the references from diagnosis, with the mean difference increasing with time from diagnosis.[3] This trend of early and increasing heterogeneity of PwMS' earnings has been postulated to be due to the disparate levels of work incapacity, influenced by severity of physical disability and cognitive function independently, and variations in flexibility of occupations and workplaces to adapt.[14 20 30 44–46] Furthermore, the level of earnings may be reduced of those who remain economically active due to truncated careers and underemployment.[9] The accumulation of irreversible physical disability of MS is highly variable and related to both age of clinical onset and current age.[42] As the disease progresses, future unbalanced changes in the component sources of DI may therefore occur through further reduced earnings due to increasing levels of work incapacity.[5 9 25 47]

In line with previous research, we identified a larger proportion of PwMS receiving income from morbidity-related benefits than references and PwMS transitioning from SA to DP benefits.[3 10 47] These patterns were not found for the reference group; the proportions of references receiving SA benefits were larger than DP for all years. Nevertheless, most PwMS were observed to not be on either benefit within our study period, further suggesting that early stages of MS morbidity were observed. These morbidity-related benefits have an increasing role in consideration of the progressive nature of MS.[10 20] SA benefits are designed to compensate periods of temporary absence from work, and following the progressive chronic characteristics of MS, permanent DP can be expected to increase with time.[3 13 21 47] Consistent with the trends we observed, the literature suggests that while SA is highest among PwMS around diagnosis years, DP grants continue to increase with time.[10 47] We observed DP surpassing SA benefits postdiagnosis. This increase of DP benefits can accordingly be expected to continue with time.[10 22 47] Such a continuation would plausibly reduce future DI development due to the lower reimbursement by DP compared with SA benefits. Furthermore, previous research in Sweden, non-specific on diagnosis, suggested an association between SA benefits and lower subsequent DI levels.[16]

Strengths and limitations

A distinctive characteristic of this explorative study that adds to its strength and external validity was the use of nationwide registers. The registers provided the most complete data available and enabled both the full inclusion of incident cases and use of DI that could capture the complexity of incomes available to PwMS in Sweden including part-time SA and DP grants alongside earnings. Such complex combinations are important to acknowledge, especially with the early focus of our observation period.[10] Our study reflects common methodological characteristics of register-based income studies of PwMS. MS status was ascertained by formal diagnosis by ICD codes. Despite the possibility for miscoding, this method was more objective than the alternative, onset of symptoms, which suffer inaccuracies from recall bias and attribution to MS.[47 48] The longitudinal design included both prediagnosis and postdiagnosis periods to observe earlier progressive aspects of MS prior to diagnosis, such as relapses and resultant changes in income sources.[4]

An important limitation of our analyses and interpretations of economic welfare is the short-term perspective. Data were available up to 31 December 2013. The diagnosis year 2009 was selected to balance considerations of follow-up length (both before and after diagnosis) and to have a cohort reflecting current treatments and policy environments, especially regarding stricter requirements for SA and DP grants.[33 34] Furthermore, short SA spells (<14 days) were missing, and the SA analyses may therefore be underestimated. However, the DI analyses were unaffected, as short spells were included within the composite indicator under earnings, because such spells are usually employer compensated except for the first uncompensated day. Our analyses assumed homogeneity within PwMS and did not consider the variation within the cohort by either sociodemographic or disease characteristics. We did not differentiate between the different grades of SA or DP benefits, which are a unique feature of the Swedish social insurance system. The cohort being early in the disease course and with high proportions still engaged in paid work, such benefits were likely to be part time for many in the cohort.[20 22 30] An additional assumption in our interpretation of economic welfare was that DI was distributed evenly within households according to need, but the actual distribution was unknown.[28 31] Furthermore, informal support by increased earnings of household members was also plausible.

Implications for policy and research

Our results reflect the combination of a responsive welfare system and the incremental progression of MS morbidity. The finding of unchanged levels and development of economic welfare, as measured by DI, in the presence of MS suggests that the morbidity-related transfer payments buffered the economic consequences of MS of reduced earnings in the years directly after diagnosis.[29] Our results suggest that society is bearing much of the economic burden associated with MS, which the

individual would otherwise experience. The observation that the economic situation does not seem to differ much between the groups implies that that the flexible system of morbidity-related benefits that differentiate morbidity situations and levels of work incapacity in allowing part-time grants is necessary for PwMS to maintain similar levels of economic welfare to the general population early in the disease trajectory.

Moreover, current focus of MS treatment is on early intervention to delay disease progression, which should further preserve work capacity for longer periods postdiagnosis.[14 22 35 48] These delaying effects of early initiated treatments have been found to extend to socioeconomic outcomes and reduce the risk of full-time DP which, in light of the lower compensation for DP benefits, could provide further protections of economic welfare.[22]

Future research is required; we did not have the opportunity to capture long-term DI changes that may occur with further disease progression and increasing work incapacity. Lastly, we did not consider PwMS older than 65 years who may experience different DI development to our study cohort as a consequence of different income sources and benefit entitlements. This would be of particular interest in the Swedish context where the prevalent MS population is comparatively older than in other European countries.[5] Our interpretations for working-aged persons with MS focused on the role of DP benefits, which are not available for older adults.

CONCLUSIONS

Our results indicate that working-aged PwMS as a group have similar DI growth to those without MS in Sweden around time of diagnosis and suggest that the potential economic impact of MS for the individual may arise later in the disease course. We found significant differences between PwMS and the population-based reference group in the individual income sources over the 12-year follow-up within both the prediagnosis and postdiagnosis periods. However, no differences were found in the levels or development of the composite measure, annual DI, at least within the first 4 years postdiagnosis. In line with its intentions, the welfare system appears to be responsive to the individuals' economic welfare early in the disease course through balancing PwMS' DI, reflected in the reduced annual earnings balanced by increased SA and DP benefits.

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Patient consent Detail has been removed from this case description/these case descriptions to ensure anonymity. The editors and reviewers have seen the detailed information available and are satisfied that the information backs up the case the authors are making.

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Data sharing statement The data cannot be made publically available. According to the Swedish Ethical Review Act, the Personal Data Act, and the Administrative Procedure Act, data can only be made available, after legal review, for researchers who meet the criteria for access to this type of sensitive and confidential data. Readers may contact professor Kristina Alexanderson (kristina.alexanderson@ki.se) regarding the data.

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